CULTURAL BELIEFS ON CAUSES OF CLEFT LIP AND/OR PALATE AND SATISFACTION OF PRESURGICAL COUNSELLING: A MULTICENTER STUDY

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ABSTRACT

Objective:

To identify the cultural beliefs on causes of cleft lip among parents and caretakers of cleft patients in a multiracial and multiethnic background society of Malaysia.

Methodology:

A descriptive cross-sectional multicenter study involving parents/primary caretakers of cleft patients. They were interviewed with questions from an adapted proforma to elicit their cultural beliefs on the aetiology of cleft. At the same time their socioeconomic demographics, barriers encountered in receiving cleft treatment and level of satisfaction with pre-surgical counselling were also investigated. The study involved three centers providing cleft care from different regions of Malaysia.

Results:

There were 295 respondents from different ethnic groups and cultural back rounds; Malays (58.3%), indigenous Sabah (30.5%), Chinese (7.1%), Indian (2.4%), and ethnics of indigenous Peninsular Malaysia and Sarawak (1.7%). Among the Malays, they mainly attribute the aetiology of cleft to God's will, father went fishing and inheritance. As for the indigenous Sabah respondents, a wide range of beliefs are attributed towards cleft. This include antenatal trauma experienced by the mother, fruit picking, and carpentry. As for the Chinese, several acts by a pregnant mother including cleaning the drains, sewing and using scissors are implicated for the cause of cleft. However, 98.3% of the parents agreed that their cultural background does not prevent the treatment of cleft. Those from lower socioeconomic background and lower education background were more likely to encounter difficulties while receiving cleft treatment which include financial constraints and transportation. Even so, there is an overall high level of satisfaction with pre-surgical counselling for cleft patients.

Conclusion:

There is a wide range of cultural beliefs among the multiethnic society of Malaysia. It shows the colorful and diverse beliefs among parents of our cleft patients. Fortunately, these beliefs do not prevent them from seeking and continuing treatment for their children. The difficulties while receiving cleft treatment were mainly of financial constraints and transportation, which were more likely to be encountered by those from lower income and lower education background. In spite of this, the level of satisfaction with pre-surgical counselling is high.

ABSTRAK

Objektif

Mengenalpasti keperceyaan masyarakat berbilang kaum di Malaysia tentang sebab berlakunye sumbing/rekahan bibir/lelangit berdasarkan latar belakang kebudayaan mereka.

Metodologi

Ini merupakan sebuah kajian rentas deskriptif pelbagai pusat yang melibatkan ibu bapa/penjaga pesakit rekahan/sumbing bibir/lelangit. Mereka disoal berdasarkan proforma yang diadaptasi tentang kepercayaan mereka terhadap penyebab sumbing/rekahan bibir/lelangit. Pada masa yang sama, latar belakang sosioekonomi mereka, halangan atau kesukaran yang dihadapai semasa meneriam rawatan untuk anak mereka dan juga tahap kepuasan kaunseling prapembedahan turut diselidik. Kajian ini melibatkan tiga institusi berlainan di negara yang menawarkan rawatan rekahan/sumbing.

Keputusan

Sebanyak 295 responden dari pelbagai bangsa dan latar belakang budaya; Melayu (58.3%), bumiputera Sabah (30.5%), Cina (7.1%), India (2.4%), Orang Asli dan bumiputera Sarawak (1.7%). Di kalangan masyarakat Melayu, antara kepercayaan tentang penyebab rekahan/sumbing ialah takdir Tuhan, bapa yang memancing, dan keturunan. Di kalangan bumiputera Sabah, antara kepercayaan mereka, cedera semasa mengandung, mengait buah dan bertukang. Bagi kaum CIna pula, membersih longkang, menjahit dan menggunting antara kepercayaan yang disuarakan. Namun, 98.3% responded mengatakan kepercayaan ini tidak menghalang mereka menerima rawatan untuk anak-anak mereka. Bagi mereka yang terdiri dari golongan pendapatan

rendah dan latar pendidikan yang rendah, mereka lebih banyak menghadapi halangan dalam menerima rawatan terutama dari segi kesempitan wang dan pengankutan. Walaupon demikian, responden mempunyai tahap kepuasan yang tinggi terhadap kaunseling prapembedahan.

Kesimpulan

Ternyata masyarakat berbilang bangsa dan budaya di Malaysua mempunyai kepercayaan yang menarik tentang penyebab sumbing/rekahan bibir/lelangit. Mujur ia tidak menjadi penghalang untuk mereka menerima rawatan anak-anak mereka. Antara halangan yang dihadapi termasuk kesempitan wang and masalah pengangkutan. Kesukaran ini lebih banyak dihadapi oleh penjaga berlatarbelakangkan pendapatan rendah dan pedidikan yang rendah. Namun begitu, tahap kepuasan mereka tentang kaunseling prapembedahan adalah tinggi.

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INTRODUCTION

Cleft surgery and consultation is mainly offered in plastic & reconstructive surgery units across the country. It is the commonest congenital craniofacial anomaly reported. These patients are generally divided into two groups, isolated cleft palate and cleft lip with or without cleft palate, occurring approximately 1: 1000 live births (Dixon *et al.*, 2011) with ethnic variation. It is generally thought that populations of Asian descent have the highest prevalence about 2 per 1000 births with Caucasian population having intermediate prevalence with 1 per 1000 and Africans populations having lowest prevalence (Cooper *et al.*, 2006). In Malaysia, it has been reported that incidence of cleft lip, cleft palate and a combination of both were to be 1 out of 941 births (NOHSS 1998). Previously in 1990, the rate of occurrence of cleft in a Maternity Hospital, Kuala Lumpur was 1.24 per 1000 live births (Boo and Arshad 1990). A study in 2005 reported that 11.9% of major birth defects in the Kinta district of the state of Perak, Malaysia were cleft lip and palate (Thong et al 2005).

The aesthetic and impairment of a cleft lip or the speech difficulty experienced by a cleft palate adult is obviously distressing. Earlier studies have shown cleft lip and/or palate patients were perceived to have lower self esteem, difficulty in the learning process, and a tendency to be more depressed and anxious. They were less social and having difficulty meeting new friends because of their deformity (Feragen and Borge 2010). Without a doubt, it will lead to psychosocial problems and negative effects for patients, parents, and family members. The functional and aesthetic problems frequently arise usually later in life such as difficulties with oral health and speech which are more pronounced once the child starts attending school. Furthermore, these children were also being teased because of their cleft and it ultimately affects their self confidence (Noor and Musa 2007).

Despite all the negative outcomes that may be faced by cleft patients, it is not uncommon to encounter a neglected cleft patient well in their adulthood in Malaysia. It raises the question ‘why the delay in treatment?’. Could it be the various obstacles encountered by these patients like financial constraints or transportation? Or is it their cultural background and beliefs toward this condition being a hindrance for treatment and subsequent follow ups?

Malaysia is a developing country with a population of 28.3 million people consisting of a multiracial and multiethnic background, with Malays, Chinese and Indians being the major ethnic groups. Minor ethnic groups that contribute to the colorful cultural background of the country includes the indigenous people of Sabah and Sarawak, the two eastern states on the island of Borneo. The perception of cleft incidence and causes attributing to it in Malaysia is rather unique and never documented before. These beliefs either have scientific basis to it or supported with explanation based on religion and folklore. Similarly, individuals in India who practice Hinduism, believe that cleft is the result of sins from a past life (Weatherley-White et al 2005). Other beliefs include witchcraft, God's will, and engaging in a behavior associated with causal power (e.g., looking at a child with a facial deformity when pregnant).

The diverse reactions towards a child with cleft are likely influence by cultural beliefs (Black et al 2009). These beliefs can have an overwhelming outcome on the patient and their family members. As mentioned, in Hinduism, clefting is a result of sins from a past life, which may lead to shame for the patients and their family. As for other beliefs, it may affect parental attachment, family interactions, and social acceptance. This can ultimately lead to discrimination, neglect, social isolation, and overall poor psychosocial adjustment (Mednick 2013).

Besides beliefs on causes of cleft, presurgical counselling for cleft patients may present as an important factor influencing success of cleft management which is frequently forgotten by healthcare personnel. The myriad of specialties involved in cleft care might take advantage and assume that these patients are obligated to seek and agree for treatment. They might employ some counselling beforehand but it could be halfheartedly which sends out a very discouraging and negative impact on the patients and family members. Satisfaction with counselling is proven to be a key factor in patient management as non-compliance to medical treatment have been associated with lower level of satisfaction (Boorman, 2001).

Early counselling has shown to help improve overall outcome of surgical procedures. Preoperative education facilitates recovery and reduces postoperative pain. This is especially true with anxious patients and those in denial of their medical condition which are scenarios commonly encountered with cleft patients and first time parents. Furthermore, effective counselling improve compliance to the overall treatment allowing a timely recovery with early discharge (Fearon et al, 2005). Rapport built between the parents, cleft patients and the treating surgeon will be a fundamental element in the delivery of an integrated cleft management.

With this study, we take the opportunity to explore and document our diverse cultural background on their beliefs regarding causes of cleft. Their level of satisfaction with presurgical counselling that is assumed to be a ‘knee jerk’ reflex among our doctors treating cleft is also investigated. Information gathered is hoped to give an insight on the cleft care in Malaysia and ultimately improve it for the future.

LITERATURE REVIEW

EPIDIMIOLOGY OF CLEFT

Cleft lip, cleft palate or both are among the most common congenital malformations. They can be collectively referred as oral clefts. Majority of these patients have isolated defects, often termed as non-syndromic or they can occur with other congenital malformations comprising of many clinical syndromes. (Dixon *et al.*, 2011). It is established that the incidence varies with ethnicity and geography. Reports from many parts of the world showed the incidence ranges from 0.8 to 2.69 per 1000 live birth. Asians were noted to have higher occurrence of cleft lip and/or palate compare to Caucasians.

The incidence of isolated cleft palate is racially homogenous at approximately 0.5 per 1000 live birth. (Vanderas, 1987). As for unilateral cleft, it is nine times as common as bilateral cleft, and occur twice as frequently in the left than the right. The ratio of left: right : bilateral clefts is 6 : 3 : 1. Males are predominantly affected in cleft lip and palate with a male: female of 2:1 whereas females are more commonly affected by isolated cleft palate. (Lieff et al., 1999; Chung et al., 2000). Unequal gender distribution of the cleft lip and/or palate is attributed to the different timing of embryological process between males and females (Davidson, 2012).

Previously in Malaysia, a study was conducted in the Kuala Lumpur Maternity Hospital. They reported the incidence of cleft was 1.24 per 1000 live birth. The highest incidence was among the Chinese with 1.9 per 1000 live birth affected, while the Malay had the lowest incidence of 0.98 per 1000 live birth. The commonest type was reported to be unilateral cleft of hard and soft palate. (Boo and Arshad, 1990).

EMBRYOLOGY

The pathogenesis of orofacial cleft requires a thorough understanding of its embryology. This is essential to the overall care and treatment of cleft patients. Traditionally, the classical theory described facial development involves multiple process of embryogenesis including formation, migration, and fusion of five facial prominences or processes. These facial prominences are the frontonasal, bilateral maxillary, and the bilateral mandibular (Durscy, 1869; His, 1874). It explains the fusion of the medial and nasal prominences of the frontonasal process with the maxillary prominences during weeks 4 to 7 of gestation results in formation of the primary palate. Later in weeks 5 to 12 of gestation, fusion of the two lateral palatal processes of the maxillary prominences forms the secondary palate. This description of facial development involves the assembly of formed structures also known as processes based on a simplified description of external morphology.

However, in the past decade, a more recent theory described the facial prominences or processes as complex arrangements of developmental fields under genetic control, not single autonomous or anatomic units (Carstens, 2002). It is thought that these early embryonic development is under genetic influence through the production of growth factors that target specific embryonic cell populations and guide their differentiation, migration and morphogenesis (Marazita & Mooney, 2004). The overall effect of normal development is not only driven by the presence of these growth hormones but also their concentration gradients and diffusion patterns which is regulated by intercellular communication and selective cell membrane permeability. Therefore, slight interference or disruption of gene-controlled, growth-factor mediated cell differentiation, migration, and fusion may result in congenital malformations (Carstens, 2002).

In Carstens' neuromeric model of developmental fields, the face is conceptualized as a series of genetically defined developmental fields, each with a specific cellular content and a recognizable functional matrix (Carstens, 2004). These individual developmental fields develop from a specific anatomic zone of the embryo called a neuromere. Neuromeres in turn are based on a segmented model of the embryonic nervous system. Unique patterns of gene expression determine the anatomic boundaries of each zone within the neural tube of the embryo.

Many of the genes within a specific zone share an identical base pair sequence called a homeobox (hox). Mapping of the neuromeric zones during development is by their hox and other zone specific genes.

As mentioned, the formation, migration, coalescence, and interaction of separate genetically based developmental fields results in overall facial development (Carstens, 2002). Disruption of a neuromeric zone results in abnormalities in the developmental field originating from that zone and will mechanically disrupt normal interactions with adjacent fields, resulting in field mismatch.

AETIOLOGY OF CLEFT

The aetiology of cleft lip and palate is heterogenous and this leads to implications in understanding the biology of facial development and the interaction between environmental risks with genetic factors. Genetics have shown to play a pivotal role in this congenital defect as 20% of cleft patients in different populations have a positive family history. Families of patients affected by the cleft lip and palate have a completely different genetic background in comparisons to those with isolated cleft lip (Goto *et al.*, 2013).

Teratogenic exposures, single-gene disorders, or chromosomal abnormalities can all lead to oral cleft and are classified as syndromic when they occur with other congenital defects as one of over 400 described syndromes (Gorlin, Cohen, & Hennekam, 2001). However, approximately 50% to 70% of cases, there are no identifiable pattern of malformation and the cause of the disorder is unknown (Gorlin et al., 2001).

These cases are classified as non-syndromic, and they can either be isolated or non-isolated, depending on whether they occur with other congenital defects (Mitchell et al., 2002). The majority of syndromic clefts have simple Mendelian patterns of inheritance but isolated clefts usually comprise of genetically complex traits (Lidral & Murray, 2004).

Previously, several molecular studies have identified mutations in genes such as IRF6 (Kondo, Schutte, Richardson, Bjork, & Knight, 2002) and MSX1 (Mossey & Little, 2002; Salahshourifar, Halim, Wan Sulaiman, & Zilfalil, 2011) can result in orofacial clefts. The study done in Malay population in Kelantan also identified a contribution of MSX1 genes in aetiology of cleft lip and palate (Salahshourifar et al., 2011).

In addition to genetic factors, other risk factors contributing to oral clefting have also been identified during early pregnancy. These include established teratogens like anticonvulsant drugs and corticosteroids (Park-Wyllie, Mazzotta, Pastuszak, Moretti, & Beique, 2000) as well as maternal smoking (Honein, Rasmussen, & Reefhuis, 2007), alcohol use (Romitti et al., 2007), and exposure to organic solvents and agricultural chemicals (Shaw, Nelson, Iovannisci, Finnell, & Lammer, 2003). Vitamin deficiencies (Munger et al., 2004) and viral infections (Acs, Banhidy, Puho, & Czeizel, 2005) have also shown to increase the risk of orofacial clefts.

PSYCHOSOCIAL FACTORS

It is quite common for patients with cleft lip and/or palate to experience discrimination and face stigma by peers and people in their surrounding may it be family members, employers or even the general public. This can be attributed to the less attractive aesthetic facial appearance, speech difficulty and hearing impairment that cleft patients have to endure. This results in cleft patients to have lower esteem, difficulty in the learning process and a tendency to be more depressed and anxious (Ramstad et al., 1995; Noor and Musa, 2007). Majority of them also felt dissatisfied with their facial appearance and desire further treatment (Hunt *et al.*, 2005).

Even though majority of cleft patients received complete treatment regarding their physical deformities, they still faced challenges and obstacles in education and marriage. It has been reported cleft patients received lower income, lower chance of employment and were dependent on their families compared with non-cleft individuals (Oosterkamp et al., 2007). Surgery being the immediate option of dealing with issues related to disfigurement, is beneficial in dealing with both physical and psychological issues. Surgery usually results in increased self-esteem, self-confidence and satisfaction with appearance (Sousa et al., 2009).

Therefore, early understanding among parents and caretakers regarding the need for multiple surgical intervention for their cleft child and lifelong follow ups and clinic visits is imperative to ensure compliance to treatment. Emphasizing the need for a multidisciplinary approach in managing a cleft patient is also another aspect that should be done early in the consultation. Finally, regardless of intervention, both patient and their parents or caretakers' expectations must be considered before and after surgery. No amount of surgery will achieve the perfect anatomy and symmetry in most of these patients. This should be well understood by both the treating surgeon and the patient.

CULTURAL BELIEFS ON CLEFT

It has been documented that in other parts of the world, causal attributions for clefts are influenced by culture and plays a vital role in people's behaviour towards seeking medical treatment (Mednick and Synder 2013). For example, certain tribes in Nigeria believed that causes of orafacial cleft were attributed to witchcraft, evil spirit or devil, the mother, and occasionally the child (Oginni and Asuku, 2010). Other ethnic groups in Nigeria such as the Yoruba people attributed the aetiology to supernatural forces (evil spirits and ancestral spirits), while the Hausa/Fulani people attributed it to the "will of God" (Olsoji, 2006). Previous report in a group of South African adults with repaired cleft lip, cleft palate, or both found that some individuals attributed the cause of their clefts to being cursed, and others mentioned that their mothers had handled sharp objects during an eclipse (Patel and Ross, 2003).

In another study in the South African setting, traditional healers were interviewed regarding their beliefs on causes of cleft. Their beliefs were related to the patients' ancestors. Ancestors were singling out the cleft baby because the child was blessed with supernatural powers. It could also be as a punishment by the ancestors towards the child's mother for attempting "to steal another woman's child because she thought she was unable to fall pregnant.'' Another explanation was that angry ancestors had caused the baby to be born with a cleft because the family had held a ritual ceremony in the wrong place.

Other beliefs reported from this study included curses from jealous people and eating poisoned rabbit meat. The term harelip used to be associated with cleft lip and/or palate because of the resemblance of the slit-like mouth found on rabbits (Dagher and Ross 2004).

A similar study by Ross in 2007 noted that Muslim and Hindu traditional healers believed that the cause of cleft was an act of God with various superstitions. This includes if a pregnant woman handled a sharp object during an eclipse, her infant could be born with a cleft (Ross 2007). According to Hindu beliefs, an eclipse is a "bad time" because during an eclipse “two planets pass each other similar to when two cars pass each other a lot of dust and pollution is created. The planets have the same effect. This pollution could affect an unborn baby if the mother does not take the necessary precautions."

In Mexico, a solar eclipse was also attributed for the cause of cleft. Pregnant women were believed to be in danger of having a baby with a craniofacial cleft if a solar eclipse were to occur (Castro 1995). In India, some of the beliefs on the cause of cleft was the result of sins from a past life (Weatherley-White et al., 2005). Other religious and cultural beliefs regarding causation of clefts include witchcraft, God's will, and engaging in a behavior associated with causal power (e.g., looking at a child with a facial deformity when pregnant (Mednick 2013).

This shows that communities from different regions of the world have interesting and colorful beliefs when it comes to the causes of cleft. These beliefs may or may not affect the overall treatment and care of cleft in the mentioned countries. In Malaysia, this has not been explored before. Being a melting pot of cultures and ethnicity, the Malaysian community will be an example of how a multiracial backround community with different beliefs on causes of cleft have an influence on the overall treatment and care for cleft.

RATIONALE FOR THE STUDY

The beliefs and attitudes of people play major role in regards to how one perceives and response towards any physical deformity. In a child with a cleft lip and/or palate, the responses are different across cultures and are likely influenced by the cultural beliefs surrounding the cause of CL/P (Mednick and Synder 2013). Therefore, these beliefs will indefinitely influence not only upbringing of the child but also when seeking medical advice for any health-related issues. Besides that, other determining factors that need to be considered in ensuring a total care approach for any cleft patient are the resources available and its limitations. Cleft patients in rural areas of Malaysia maybe having difficulties in receiving the optimum care they require and this is something that that should be investigated and improved in the future. Practicing Plastic Surgeons play a vital role in providing the necessary information and education from the beginning for the parents and the patients. By assessing the effectiveness and the adequacy of the initial consultation, it will give an insight as to how effective it was and whether it is enough. This will give the opportunity the opportunity to improve the cleft services in the future.

The proforma utilised has been adapted from previous studies to probe even more on the study topic. The demographics and socioeconomic background of the participants are being collected as well as their perception and beliefs towards causes of cleft. Besides that, issues regarding early counselling and possible factors that may cause difficulty in the treatment are also being probed.

The centers that were chosen for the study were based on the fact that these centers are the main Plastic Surgery centers providing cleft care in their regions. They also represent different socioeconomic backgrounds that reflect the multiethnic and multicultural background of the country.

The purpose of this thesis is to investigate the cultural beliefs towards the cause of cleft in a multiethnic and multicultural community of Malaysia. It also explored into the barriers encountered by these patients and their family in seeking treatment for their condition. By gathering such data, we can document these cultural beliefs and preserve it for future generations. We also investigated on the satisfaction of pre-surgical counselling among caretakers of our cleft patients. With all this information gathered, we will have the opportunity to acknowledge their beliefs on cleft and how they about the cleft service available in this country. This will be the stepping stone to improve the overall cleft management and open doors for future research and investigation on cleft in Malaysia.

OBJECTIVE

General

To investigate the cultural beliefs on causes of cleft lip and palate and factors influencing its management

Specific

1. To determine the socioeconomic demographic factors of parents/caretakers (relationship with cleft patient, education, household income, marital status) of cleft patients
2. To identify the cultural beliefs among the parents/caretakers on causes of cleft lip and palate
3. To determine barriers encountered by parents/caretakers in receiving treatment for cleft lip and palate patients
4. To determine level satisfaction in receiving presurgical counselling for cleft lip and palate patients

Study Hypothesis

There is a wide range of cultural beliefs among the multiethnic groups in Malaysia in regards to the causes of cleft and factors influencing the management of cleft patients.

Cultural Beliefs on Causes of Cleft Lip and/or Palate and Satisfaction of Pre-Surgical Counselling Among Parents/Caretakers: A Multicenter Study

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Satisfaction of Presurgical Counselling Among Parents/Caretakers of Cleft Lip and/or Palate Patients and Their Cultural Beliefs on Aetiology of cleft: A Multicenter Study

1.0 Introduction

1.1 Cleft lip and/or palate considered to be the main bulk of patients being treated and consulted in any Plastic Surgery unit. It is the commonest congenital craniofacial anomaly encountered by plastic surgeons worldwide. These patients are generally divided into two groups, isolated cleft palate and cleft lip with or without cleft palate. These defects arise in about 1·7 per 1000 live born babies, with ethnic and geographic variation. It is generally thought that populations of Asian or Native North American descent have the highest prevalence, with Caucasian populations having intermediate prevalence and African populations having the lowest prevalence (Gorlin et. al., 2001). In Malaysia, it has been reported that incidence of cleft lip, cleft palate and a combination of both were to be 1 out of 941 births (NOHSS 1998). Previously in 1990, the rate of occurrence of cleft in a Maternity Hospital, Kuala Lumpur was 1.24 per 1000 live births (Boo and Arshad 1990). A more recent study in 2005 reported that 11.9% of major birth defects in the Kinta district of the state of Perak, Malaysia were cleft lip and palate (Thong et al 2005). Therefore, cleft patients are commonly encountered by many disciplines, not just by plastic surgeons in Malaysia.

1.2 It is well understood by many that total cleft care involves a multidisciplinary approach. Treatment and management of this common craniofacial anomaly prompts intervention from day one of life, may it be early counselling or splinting of the cleft. In centres of well developed countries, regular antenatal follow ups with early scans for families with positive family history of cleft lip and/or palate are commonly practiced.

1.3 The aesthetic and impairment of a cleft lip or the speech difficulty experienced by a cleft palate adult is obviously distressing. Earlier studies have shown cleft lip and/or palate patients were perceived to have lower self esteem, difficulty in the learning process, and a tendency to be more depressed and anxious. Besides that, they were less social and having difficulty meeting new friend because of their deformity (Feragen and Borge 2010). These without a doubt will lead to psychosocial problems and can have negative effects not only for the patients but also the caretakers

especially parents and other family members. The functional and aesthetic problems frequently arise usually later in life such as difficulties with oral health and speech. This is more pronounced once the child starts attending school. Furthermore, these children were also being teased because of their cleft and it ultimately affects their self-confidence (Noor and Musa 2007).

1.4 With all the evidence pointing towards negative outcomes in any child's upbringing, it raises the question: 'why the delay in treatment?'. In Malaysia, it is quite common to see neglected adult cleft lip or palate patients walking about in the public, more common in some parts of the country than others. There has not been any documentation as to why these patients delay the treatment. In Malaysia, plastic surgery services have started since 1970. Hospital Kuala Lumpur, located in the countrie's capital city of Kuala Lumpur, is a pioneer in cleft surgery and has since then always put cleft surgery and its management as its main agenda.

1.5 Malaysia being a developing country with a population of 28.3 million people consisting of a multiracial and multiethnic background, with Malays, Chinese and Indians being the major ethnic groups, the perception of cleft incidence and causes attributing to it is rather unique and never documented before. It has been documented that in other parts of the world, causal attributions for clefts are influenced by culture and plays a vital role in people's behavior towards seeking medical treatment (Mednick and Synder 2013). For example, certain tribes in Nigeria believed that causes of orafacial cleft were attributed to witchcraft, evil spirit or devil, the mother, and occasionally the child (Oginni and Asuku, 2010). The term culture, is defined as the total way of life of individuals. Across the globe, the is variations in cultural beliefs, concepts, and practices that affect our daily living activities. With culture and knowledge, coupled with the current accessibility to information, it represents a powerful determinant in influencing the behavioral pattern of individuals. It also can be a major determinant of health-seeking behaviors in any society. It has been observed that treatment of birth defects and other disabilities is influenced by many factors. This includes the cultural beliefs of the individual, family, and society, as well as folk and traditional religious beliefs (Cheng, 1990) and of course their knowledge of the particular condition. Multiple factors affect the therapeutic process in orofacial clefts which include the attitudes of patients, their families, and their community (Patel and

Ross, 2003). Futhermore, cultural diversity that exist in a community will have effect on how families and professionals get involved in treatment programs. Interventions need to be culturally sensitive due to the differences across varying ethnicities and cultures in terms of parental and extrafamilial influence (Broder, 2001). Therefore, the total care of any condition, not just orofacial cleft requires and in depth understanding and identification of culturally based beliefs and assumptions. For example, as previously reported in other parts of the world like China, a pregnant woman should not eat rabbit meat for fear of giving birth to a baby with a ‘‘harelip’’ (Cheng, 1990).

1.6 Being a developing country, Malaysia is not shy from its limited resources in managing cleft patients. It may be due to limited resources in terms of practicing cleft surgeon or simply the limited public transportation getting to the nearest healthcare facility as seen in some parts of East Malaysia in the island of Borneo.

1.7 However, treatment of any medical condition does not begin with the practicing doctor but with the patient him/herself and his/her surroundings including the parents and caretakers. This includes the beliefs that the patient and his/her caretaker have been taught or grown up with pertaining to his/her medical condition.

1.8 Furthermore, as plastic surgeons, it is not only important to provide the surgical and medical care for cleft patients but also to counsel and understand patients’ background as well as educate them regarding their conditions and provide not only the necessary information but also the correct one.

Ultimately, the goal is for the child to be able to achieve his or her full potential and able to function well in the society later in life and minimize as much as possible the complications. Therefore, a holistic approach to any cleft patient involves many medical and non-medical specialties but also others involve in any child’s developmental growth, may it be parents, grandparents, teachers and relatives. Every surgeon involved in managing patients with cleft lip and palate aims for an excellent aesthetic and functional outcomes. This is important to improve the patients’ quality of life as a whole. There are many factor influencing the success of the optimum care for these patients. By looking into some of the factors, it will better the services provided to them in the future.

2.0 Objectives

2.1 General

To investigate the cultural beliefs on causes of cleft lip and palate and factors influencing its management

2.2 Specific

1. To determine the socioeconomic demographic factors of parents/caretakers (relationship with cleft patient, education, household income, marital status) of cleft patients
2. To identify the cultural beliefs among the parents/caretakers on causes of cleft lip and palate
3. To determine barriers encountered by parents/caretakers in receiving treatment for cleft lip and palate patients
4. To determine level satisfaction in receiving presurgical counselling for cleft lip and palate patients

2.3 Study Hypothesis

There is a wide range of cultural beliefs among the multiethnic groups in Malaysia in regards to the causes of cleft and factors influencing the management of cleft patients.

3.0 Justification of the studying

The beliefs and attitudes of people play major role in regards to how one perceives and response towards any physical deformity. In a child with a cleft lip and/or palate, the responses are different across cultures and are likely influenced by the cultural beliefs surrounding the cause of CL/P (Mednick and Synder 2013). Therefore these beliefs will indefinitely influence not only upbringing of the child but also when seeking medical advice for any health related issues. Besides that, other determining factors that need to be considered in ensuring a total care approach for any cleft patient are the resources available and its limitations. Cleft patients in rural areas of Malaysia

maybe having difficulties in receiving the optimum care they require and this is something that that should be investigated and improved in the future. Not only that, practicing Plastic Surgeons play a vital role in providing the necessary information and education from the beginning for the parents and also for the patients. By looking into the effectiveness and the adequacy of the initial consultation, it will give an insight as to how effective it was and wether it is enough. This will give the opportunity the opportunity to improve the cleft services in the future.

The proforma used has been adapted from previous studies to probe even more on the study topic. The demographics and socioeconomic back ground of the participants are being collected as well as their perception and beliefs towards causes of cleft. Besides that, issues regarding early counselling and possible factors that may cause difficulty in the treatment are also being probed.

The centers that were chosen for the study were based on the fact that these centers are the main Plastic Surgery centers providing cleft care in their regions. Not only that, they also represent different socioeconomic backgrounds that reflect the multi ethnicity and multicultural background of the country.

4.0 Methodology

The study is conducted in various centres in Malaysia providing cleft services including Hospital Kuala Lumpur, Hospital Universiti Sains Malaysia, Kubang Kerian, Hospital Raja Perempuan Zainab, Kota Bharu, and Hospital Queen Elizabeth Kota Kinabalu, Sabah. This is a descriptive cross-sectional study on parents/primary caretakers of cleft patients who seeks or have been receiving medical treatment regarding cleft lip and/or palate in hospitals mentioned. All parents/caretakers will be interviewed using questions in the proforma via telephone call. This is to get the cohort of patients age ranging from newborn to adulthood.

Contacts of all cleft patients that are under follow up will be traced from various sources. This include previous operating lists, outpatient clinic registration, and ward admission records. Besides that, recruitment of subjects will also be from the delivery list in the neonatal units/labour room of the mentioned centers. Based on these lists, the patient details and contacts can be determined and will further be contacted via

phone for participation of the study. The subjects will be selected if they fulfil the criteria as below:

1. Primary caretakers/parents of nonsyndromic cleft lip and palate
2. Has had previous follow up or currently under follow up for cleft lip and/or palate
3. Consented for participation of study
4. Malaysian citizen

By doing this, random sampling of the subjects will be conducted. Once selected, patients' parent/caretakers will be contacted via telephone and verbal consent obtained. Issues regarding vulnerability of subject will be explained as there is very minimal risk in participating in the study as all the involved patients have already been diagnosed before and already on follow up. Issues on confidentialty is also emphasized as all the information collected is without any revelation on their identity. There is also minimal risk to the spouse or partner of participating subjects as they are also well aware of the diagnosis and already being part of the treatment plan and follow ups. The interview will be conducted either in English or Bahasa Melayu and will follow the dialogue as below:

English version

Investigator: "Greetings Mr/Mrs _____(caretakers/parents name). My name is _____ (investigator's name) and I am a researcher from _____(hospital). Currently I am doing a study on satisfaction of presurgical counselling among parents/caretakers of cleft lip and/or palate patients and their cultural beliefs on aetiology of cleft. It involves an interview with a series questions and will approximately take 5-10 minutes of your time. Would you be interested to participate in this study?"

Bahasa Melayu version

Penyelidik: "Selamat sejahtera En/Pn _____ (nama penjaga). Nama saya _____ (nama penyelidik) dan saya seorang penyelidik dari _____ (nama hospital). Saya sedang menjalankan suatu kajian tentang kepuasan di kalangan ibu bapa/penjaga pesakit sumbing berkenaan kaunseling prapembedahan dan kepercayaan masyarakat mereka tentang penyebab sumbing. Ia melibatkan sesi

temuramah yang merangkumi beberapa soalan dan mengambil masa encik/puan 5-10 minit. Adakah encik/puan berminat untuk menyertai kajian ini?”

If they agree to participate in the research, they will be asked a set of questions for them to answer based on the proforma created.

The proforma consists of 35 questions enquiring about their socioeconomic demographic as well as emphasising on the objectives of the research touching on their cultural beliefs regarding causes of cleft lip and/or palate and their satisfaction of presurgical counselling.

The participants will answer the question independently with the help of researcher if necessary. Participants who did not answer at least 75% of the items were not included in the analysis.

4.1 Sample size

Using single proportion formula:

$n = (z/\delta)2\ (p(1-p))$

$Z = 1.96$

$\delta = 0.05$

P = proportion

Anticipating a 20% nonresponse

variable	proportion	precision	n	n+20%	literature review
age group (0-20)	7.4%	0.05	100	120	Ogini et al 2008

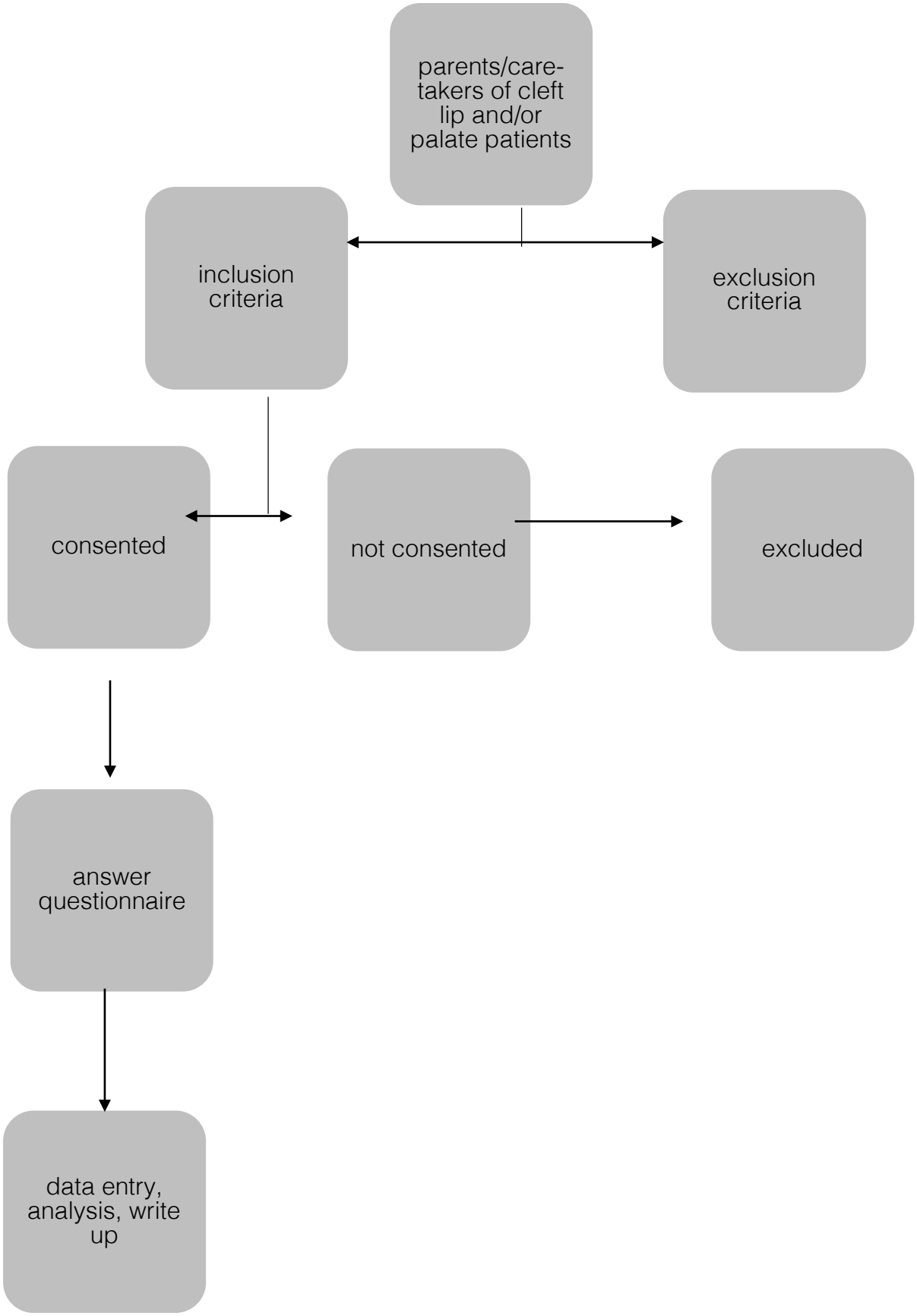
4.2 Sampling Method:

We will apply simple random sampling method from the list of contatcs obtained to choose 120 subjects from the hospitals mentioned.

4.3 Data Analysis

Data will be entered into a computer and analyzed using Statistical Package for the Social Sciences (SPSS) statistical software (SPSS, Inc., Chicago, IL). Simple descriptive statistics, chi-square tests, and Pearson correlations will be used. A p level of <.05 will be considered statistically significant

4.4 Flow chart



4.4 Gantt Chart

YEAR					2	0	1	6						2	0	1	7
MONTH	JAN	FEB	MARCH	APR	MAY	JUNE	JUL	AUG	SEPT	OCT	NOV	DEC	JAN	FEB	MARCH	APR	MAY
PROPOSAL																	
DATA COLLECTION																	
DATA ANALYSIS																	
WRITING																	

5.0 Expected Outcome

This study on the beliefs across cultures in regards to clefts and its causal attributions in a multiethnic country such as Malaysia will be a stepping stone towards better understanding the cleft patient as a whole. Not only the medical and surgical care should be provided in the holistic management of cleft patients, but also the cultural background and beliefs that influences them to seek and receive such treatment. By doing this, it will improve the total cleft care as advocated by many world wide. Not only that, probing on the issue of pre surgical counselling in these patients will give an insight for surgeons on how much they influence the management from day 1 of consultation. This will benefit to better the service currently being provided and improve it in the future.